

**Building and Strengthening Capacity to Promote and Maintain High Quality Care For Medicaid
Beneficiaries
Breakthrough Series Collaborative on Improving Care for Children with Attention Deficit
Hyperactivity Disorder**

**Project Summary
September, 2000 – October, 2002**

This report will describe the implementation and results of the project, Breakthrough Series Collaborative on Improving Care for Children with Attention Deficit Hyperactivity Disorder, that was a project of the developing partnership between the University of North Carolina Children's Primary Care Research Group (CPCRG)/National Initiative for Children's Healthcare Quality (NICHQ) and the North Carolina Division of Medical Assistance (DMA). This project intended to develop, measure, promote and disseminate positive changes to improve care in primary care practices that serve Medicaid recipients. This report will discuss the Breakthrough Series Collaborative on Improving Care for Children with Attention Deficit Hyperactivity Disorder (ADHD), realizing that the same methodology could be used for any other disease specific or preventive condition.

NC IMPROVEMENT COLLABORATORS: CPCRG, NICHQ AND NC DMA

The Children's Primary Care Research Group (CPCRG)

The Children's Primary Care Research Group at the University of North Carolina was formed in 1993 to improve the health and development of children and adolescents by increasing the focus on outcomes, effectiveness and accountability at every level of pediatric practice: patient care, practice management, child health policy, and medical education. The CPCRG's vision is to work in partnership with physicians, communities and health systems to develop, test and disseminate strategies designed to improve the clinical effectiveness of health care for children and adolescents. A major emphasis is on linking clinical and public health efforts to improve the health of children and youths. A premise of the research group's philosophy is that better health will result from an integration of individual and population-based approaches.

In 1999, the CPCRG collaborated with colleagues doing similar work in Boston, Vermont, and Seattle to create the National Initiative for Children's Healthcare Quality. CPCRG works closely with NICHQ to develop and implement programs to improve the healthcare that children receive.

The National Initiative for Children's Healthcare Quality (NICHQ)

The National Initiative for Children's Healthcare Quality (NICHQ) is an education and research organization dedicated solely to improving the quality of health care provided to children. Founded in 1999, NICHQ's mission is to eliminate the gap between what is and what could be in health care for all children. A national organization with its home office in Boston, NICHQ also has offices in Vermont, Washington State and North Carolina.

Led by experienced children's health care professionals, NICHQ works to improve children's health care independently and by working in collaboration with others who share this goal. Specifically, NICHQ:

- ***Raises Awareness***
NICHQ calls attention to the need for better children's health care, and spreads stories of success that demonstrate care can be improved to produce better outcomes.
- ***Helps Clinicians and Practices Improve Care***
NICHQ provides tools and methods to improve systems of care and assists physicians and their staffs to make changes based on the best available evidence for good practice.
- ***Undertakes Research***
NICHQ works on its own and in collaboration with others to identify best practices in pediatric care and seeks to be the premier resource for the most effective methods for improving health care for children.

NICHQ connects organizations and individuals who care about children with those who are experts in improvement. NICHQ's core services include educational programs, regional improvement partnerships, and its quality performance data system. Educational programs include the Learning Collaborative, which brings together up to 40 health care organizations to work and learn together about how to improve care and service in a specific area. Under expert guidance, these organizations work collaboratively for up to a year or more, testing and sharing improvement ideas and successes.

Statement of the Problem

Attention Deficit Hyperactivity Disorder (ADHD) is the most common behavioral health condition that affects children. As many as 5-12 % of school aged children are on stimulant medication, and the increasing use of psychotropic drugs in childhood has raised widespread concern among policy makers about cost and outcomes. At the same time, ADHD inflicts enormous morbidity on children with this condition and on their families. Children with this disorder experience profound social isolation, with impaired social skills a common component of the disorder. Families of these children also become isolated, either unable to manage their child's behavior in group settings, or embarrassed about their child's performance despite normal external appearance and intelligence. Long-term outcome data indicate these children are at increased risk of school failure, joblessness, and even criminality. Excellent evidence exists about what elements of care are effective to improve outcomes for children with this disorder. Dismaying evidence also exists that most children with this disorder do not receive the type of care that this best evidence would suggest.

Most children with ADHD are diagnosed and managed by primary care clinicians; some complex cases also involve the mental health system. The majority of children with ADHD also receive special education or counseling services in their schools. Efforts to enhance care and outcomes for these children must be focused on primary care but must also encompass the mental health and education systems.

The National Initiative for Children's Healthcare Quality is a program of the Institute for Healthcare Improvement, the premier organization focused on quality improvement in health care. NICHQ's mission is ambitious—to eliminate the gap between what is and what can be in health care for all children. NICHQ is committed to dramatically transforming the quality of care that children with ADHD receive as one of its major initiatives, and has already begun some activities in this area. NICHQ is seeking support from the Robert Wood Johnson Foundation to enable us to accelerate that effort, both broadening our scope and intensifying our activities.

Project Description

1. General Purpose of the Project

Substantial evidence exists concerning optimal means to identify and treat ADHD, the most common behavioral health condition that affects children. The Agency for Healthcare Research and Quality, through its Evidence-based Practice Center program, has assessed and summarized this evidence, and produced two evidence reports. These reports form the foundation for clinical practice guidelines developed by the American Academy of Pediatrics. The purpose of this project was to promote the translation of the evidence about the diagnosis and treatment of ADHD into clinical practice

The long-term aim for the National Initiative for Children's Healthcare Quality's activities in this topic area is to improve the care for children with ADHD, by dramatically transforming the quality of the health care that they receive. The specific aim in offering a Breakthrough Series Collaborative, is to make major changes in their systems of care and the outcomes that their children with this disorder experience. Primary care clinicians, their office teams and their community school and mental health partners were the primary targets for this collaborative. In addition to achieving change in the participant practices, the collaborative sought to

- Refine tools and materials that could be used to facilitate implementation of evidence based care,
- Test and refine practical measures of processes and outcomes that practices and systems could use to track improvement, and
- Develop exemplar models of care that could facilitate dissemination by demonstrating the feasibility of improvement.

The innovations developed and tested through this collaborative learning process form the seed for continued efforts to change care extending beyond this project.

2. Planning Process

In approaching this collaborative, NICHQ followed the well-established planning process developed by the Institute for Healthcare Improvement for its many "Breakthrough Series" collaboratives. The key planning activity for the broader NICHQ strategy was to establish key partnerships that would facilitate the broad diffusion of innovations developed through the collaborative learning process. Planning activities for this specific collaborative have included:

1. Identification of topic chairs: Mark Wolraich, MD, Director, Child Study Center, Oklahoma City, OK and Peter Jensen, MD, Center for the Advancement of Children's Mental Health, Columbia University, New York, NY and served as chairs of this Breakthrough Series Collaborative.
2. Convening of Expert Meeting: In September 2000, NICHQ hosted an expert meeting to define the specific change concepts that would be used to drive the activities of participating teams. This expert panel also began to identify measures that teams could use to track their performance. The expert group included researchers, practitioners who have developed and implemented model systems of care, educators, mental health providers, and parent advocates. (Appendix A)
3. Adoption of chronic care framework - NICHQ has adapted the Chronic Care Model developed by Ed Wagner as the broad framework for care for children with this and other chronic conditions. The expert panel endorsed the use of this framework in this collaborative. Specific change concepts identified by expert faculty were organized by component of the care model framework. (See Appendix B for framework material: the Care Model for Child Health)
4. Development and pilot testing of tools and measures—The expert panel specified the need for a variety of tools that would provide practical assistance to practitioners, including a written management plan, summaries of medications and of behavioral therapies, and monitoring instruments. In addition, the panel suggested specific measures that could be used to identify

gaps in performance and track improvement over time. As a result of the meeting, NICHQ staff identified or developed tools and measures, and undertook extensive pilot testing in a limited number of practice sites.

5. Selection of planning group – The collaborative chairs (Drs. Wolraich, Jensen) and NICHQ leadership (Homer) selected a smaller team to serve as the planning group for the collaborative from members of the collaborative Expert Faculty. The planning group met July 23, 2001 to finalize the measurement strategy and plan the agendas for the first Learning Session. The planning group guided the teams throughout the collaborative.

3. Topics selected for discussion

In order to accomplish the aims of the collaborative, topics for discussion during the collaborative focused not only on the clinical content specific to the condition of ADHD but also on the components of a system framework for the care of this disorder and on the methods for improving systems and spreading those improvements to a wider audience. Substantial time during the conference component of the collaborative was provided for teams to actually engage in planning of specific changes at their health care site, and they were coached on the changes that they are planning to make.

ADHD Clinical Content – The clinical content followed the general approach used by the AAP's clinical practice guidelines. Specifically, this entailed examining first the assessment and diagnosis, and subsequently the treatment and ongoing management. Assessment content included the use of DSM criteria, evaluation for co-existing conditions, use of standardized assessment tools, and collection of data from multiple reporters (teachers, parents, others). Treatment and management content included the relative roles of medication and behavioral therapies, specific choices for each, and methods and tools for follow up assessment and monitoring.

System Framework--Chronic Care Model –All of the collaborative content and process were framed in the context of implementing a system of care for children with chronic conditions. Wagner and colleagues developed the model we used. (Wagner, 1996) This framework provided a systematic approach to chronic care based on extensive review of the literature on health care systems that work for persons with chronic conditions, and expert panel review. Specific topics included a broad overview of the framework, as well as individual breakout sessions on each of the components of the model:

1. Self-Management Support – provides effective behavior change interventions and ongoing support, emphasizes the patient's and family's active role in managing illness
2. Community Partnerships – form partnerships with community organizations (schools) to develop programs and policies to support chronic care
3. Delivery System Design – embeds evidence-based guidelines into daily clinical practice, provide care in planned visits.
4. Decision Support – see Clinical Information System below
5. Health Care Organization – include measurable goals for ADHD as part of the organization's business plan, benefits designed to promote good chronic care, use effective improvement strategies that result in comprehensive system change in the other components.
6. Clinical Information System – Teams will be specifically taught about the use of patient registries in clinical practice.

Methods for Improvement –Teams were taught a general approach to making changes and improvements in their health care systems. This approach has been successful in other improvement activities undertaken by the Institute for Healthcare Improvement. It entails asking three fundamental questions about improvement (aims, measures, and ideas) and then mandates the use of frequent, small testing cycles (Langley, 1996).

Because measurement plays a key role in any efforts at improvement, both general and breakout sessions focused on measurement for improvement. Standardized scales based on rigorous empirical method and normative data were used for the diagnosis and assessment of ADHD. For monitoring of patients the critical elements of scales used for research were shortened to make sure measures were practical and would work in a practice setting.

In addition to learning about this specific method for improving performance, teams and organizations were taught about how to spread innovations across organizations. The framework for this topic drew heavily from Rogers' theories on the *Diffusion of Innovation*. (Rogers, 1995) As part of this same set of topics on making and spreading improvements, specific sessions also emphasized the role of leadership in promoting change.

Team meeting and action period planning session - small group sessions where members of the practice teams worked together to develop individualized action plans for improving ADHD care at their site. During these sessions faculty circulated among the teams to offer practical coaching on changing their office systems.

4. Format for the collaborative

The Institute for Healthcare Improvement's Breakthrough Series

In 1995, IHI, under the leadership of Dr. Berwick, developed the Breakthrough Series (BTS) to bring together health care organizations that share a commitment to making major, rapid changes in order to produce breakthrough results. The driving vision of the BTS is that sound science exists on the basis of which the costs and outcomes of current practice can be greatly improved, but much of this science lies fallow, unused in daily work. There is a gap between what we know and what we do. The Breakthrough Series is designed to close that gap. Each BTS Collaborative includes teams from 20 to 40 health care organizations focusing on a single topic--gathering and studying the latest scientific information available on improving specific clinical or operational areas and learning effective means to put that knowledge into practice.

NICHQ ADHD Breakthrough Series Collaborative

In this specific collaborative, practice teams participated for 12 months. The 3 key components to all learning collaboratives are training, tools, and support:

Training: Teams from each delivery organization or practice initially came together for interactive, problem-oriented training to learn more about innovations in ADHD care and strategies to implement these changes into their office setting. In plenary and breakout sessions they heard about new approaches to ADHD, quality improvement and the chronic illness framework, from experts in ADHD care and quality improvement. In small group sessions members of the practice teams worked together to develop individualized action plans for improving ADHD care at their site. During these sessions faculty circulated among the teams to offer practical coaching on changing their office systems. Teams left with strategies identified that they would test at their site. They were prepared to apply initial changes immediately after the conference. Teams included at least one physician and one other staff person (clinical or administrative).

Tools: NICHQ also provided practical tools to improve ADHD care. NICHQ used the core components of the American Academy of Pediatrics guidelines for the diagnosis and treatment of ADHD. NICHQ

developed a framework that defined the essential requirements for providing excellent care to children with ADHD.

Training sessions were different than didactic CME programs; in addition to learning about key elements specific to ADHD care, participants learned about the essential components of management of all chronic conditions. Finally, the participants learned about effective strategies to implement change in their practice setting. Training sessions were highly interactive and action oriented—the objectives were to plan real changes that practice teams would make when they returned to their care setting.

Support: Between sessions, faculty assisted practices through coaching calls, email discussion groups and a web based extranet where data and results as well as tools and documents were shared. Participants in the collaborative also received comparative data about their practices in order to guide improvement activities.

6. Expected product

As noted above, the primary aim of the collaborative was to produce major changes in the delivery provided by the participating sites. Even at this level, however, the collaborative charged these teams with responsibility to spread their successes to other sites across their organizations. National teams qualified for scholarships based on their documentation of their ability to impact these widespread changes and North Carolina teams' selection was as a result from reviewing Medicaid claims data which included the number of Medicaid patients seen, the high dollar volume of ADHD medications prescribed, and readiness to commit to the work of the year-long learning collaborative.

One of NICHQ's key organizational partnerships also spread the work of the collaborative. The American Academy of Pediatrics contracted with NICHQ for the development of a toolkit for widespread dissemination to AAP members. This toolkit was created by the pilot teams and expert faculty and will be used extensively during the ADHD Collaborative by the participating teams.

7. Participants

Participating sites in this collaborative were selected from across the country based on their potential for making breakthrough improvements in care and their potential to serve as sources of spread across larger entities—such as professional societies, managed care organizations and primary care practice networks, North Carolina State Medicaid program, and others. Special emphasis was provided to sites that met these criteria and also served indigent and minority communities. National teams received scholarship funding and NC Division of Medical Assistance sponsored North Carolina teams.

Primary care practice teams were multidisciplinary and represented physicians, nurses, administrative/front desk office staff, and support staff (medical records, information systems/data, etc.) These teams were ideally comprised of 4-6 individuals and 2-3 of those members attended the collaborative learning sessions. The collaborative required change in a practice culture and infrastructures as well as specific changes in aspects of patient care so units that support the improvement team also participated at the practice site. These supports included: Information systems, Medical Director, Finance, Network Quality Improvement Departments, Human Resources, among others – depending on the size and complexity of the practice site.

8. Evaluating the conference's success

NICHQ utilized the Educational Design Criteria established by the ANCC to plan and implement all educational offerings provided by the institution. These offerings are built on the educational expertise of the organization and its commitment to improving the quality of health care. Programs were designed, implemented and evaluated using criteria from the Massachusetts Nurses Association, including: Learner's achievement of each objective, teaching expertise of each presenter, relationship of objectives to overall purpose / goals and appropriateness of the physical facilities, location, and scheduling. In addition to the evaluation of the three learning sessions NICHQ also evaluated the participant teams ability to achieve the aims of the collaborative as demonstrated by improvement in the measures identified. The team's progress was tracked through a process of ongoing data collection and monthly progress reports. Category 1 Continuing Medical Education credit was granted by the Institute for Healthcare Improvement a CME provider.

Recruitment Strategies

Based upon our experience and learning from the previous North Carolina Asthma Learning Collaborative, a streamlined, focused recruitment strategy was planned and implemented and efforts were made simultaneously on several fronts. It was learned that several important and foundational conditions must be in place for participating practices to not only commit but to stay actively involved throughout the tenure of the 12-month long collaborative. These learnings include:

- A culture of staff from various levels of the practice working together as a team e.g., lead physician, another clinical member (usually a nurse), and someone from the administrative team,
- The support and participation of practice leadership upon initiation and throughout the collaborative, and
- Attendance and participation at all face-to-face sessions, participation on monthly teleconference calls and listserv discussions and submission of monthly data and reports which 'measure' changes over the life of the collaborative.

Targeting Practices for Recruitment

In order to impact the largest number of children with ADHD, aggregate Medicaid ADHD claims data was reviewed and several parameters set for recruitment:

- Must be a Carolina Access provider and provide care to a large number of Medicaid children,
- The practice has a high ADHD medication count,
- The practice has a large ADHD medication expense claim history, and
- The practice will extend its reach to children with ADHD by involving community partners e.g., mental health providers, schools and parents.

Additionally, direct invitations were extended to teaching facilities, which not only train new and upcoming pediatricians but also treat a large number of children with ADHD. Through the efforts of Drs. Jane Foy and Marian Earls outreach was made to NW AHEC counties to help develop local school and mental health provider resources and a team from the Child Health Services from the Guilford County Health Department applied and participated in the collaborative.

Recruitment materials were sent to the North Carolina Pediatric Society membership (1500 members) and Medicaid and CPRG staff directly targeting potential practices made phone calls. Interested parties

were able to attend and ask questions about the collaborative at several scheduled informational teleconference calls which expert faculty and staff led. Of the original 50 Medicaid claims data providers, 20 applied and met the required criteria. Acceptance letters were sent, a pre-Learning Session teleconference call was held and pre-work packets were sent to all participants.

Instruments

The following instruments were used to evaluate improvements in ADHD care at primary care practices and as an overall assessment of ADHD learning collaborative.

Patient Registry

The ADHD Patient Registry was a database created in Microsoft Access and was used for data collection. Data base management, assessments, and data analysis were key components of the Care Model. Access registry data base information was requested by NICHQ from the teams on the 7th of each month. For those teams who were unable to utilize the Access registry due to computer incompatibility, a paper version of the registry was supplied. NICHQ supplied monthly feedback reports/graphs on required measures using the registry data. Technical support for a Microsoft Access database proved difficult throughout the Collaborative. NICHQ is currently investigating web based registry products for use in future collaboratives. (See Appendix C for Paper Registry)

Monthly Progress Reports

Each practice completes a monthly report identifying changes that were tested and/or implemented and the results from those changes. The project director and in North Carolina, the NC Liaison, reviewed reports to understand specific changes for each team and to assess team's understanding of improvement methods (small tests or cycles). These changes were then identified on the monthly data reports to determine if the process and outcome measures improve as a result of making these changes.

Project Director's Monthly Report

Each month the project director and improvement advisor wrote a report on the status of the learning collaborative. The report identifies the participating teams; the aims of the Collaborative; monthly data measures for the collaborative; issues that were addressed during the month; and aggregated data that assessed how teams were rated by the director, the mean team rating for that month; number of teams that submitted a monthly report; number of teams that submitted data that month; and percent of teams that were rated a 4 or above on a 5 point Likert scale. The purpose of this report is to assess collaborative progress. This is discussed with the Improvement Advisor on a monthly basis. Strategies are developed to address trends and problem areas. (See Appendix D: Assessment Scale)

Evaluation of each Learning Session

Each learning session was evaluated by participants to determine if the stated objectives were achieved, if the topic discussed was pertinent to stated objectives, if the purposes and goals of the session were met, and if appropriate teaching strategies were used. All physician and nurse attendees had the opportunity to earn CME and CEU credits for attending these learning sessions.

Learning Session Activities

The three, two-day, face-to-face learning sessions were designed to achieve varied goals. The first learning session was designed to engage the teams in the improvement work, share clinical information and teach them the Care Model and quality improvement strategies. At the first learning session expert NICHQ and ADHD faculty led each session. After teams used the first action period to attempt improvements at their sites the second learning session was designed to share and accelerate the successes they had experienced. Best practice teams were asked to present their experiences and the participants

took an active role in presentations. By the third learning session team members took an even more active role.

Action Period Activities Overview

The time after the Learning Session was called the Action Period. During the Action Period, practice teams worked within their practice to test and implement an approach to improving the management of ADHD. These activities were opportunities to determine what strategies would lead to meaningful improvement in each practice setting. Teams collected small samples of data and tracked progress toward aims during the Action Period. Teams were expected to collect data on a monthly basis throughout the 12 months of the Collaborative. These data were reviewed and discussed at project team meetings and project staff would make individual coaching calls to practices offering support and to assist with challenges as they arose.

Conference Calls

Another feature of the Action Period was the **monthly conference calls**. Practices called into a central number and participated on a call with other practices in the Collaborative. NICHQ faculty and staff provide guidance, support and information during these calls. The purpose of the calls was for teams to describe their tests of change and share learning gained through successes and failures. These calls generally were scheduled during lunch and typically lasted for 45 minutes to 1 hour. Conference calls were well attended.

List-serve Communication

In order to facilitate communication among Collaborative participants, NICHQ used an email list serve.

Extranet

NICHQ developed, through its website, a project Extranet for all members of the Improving Care for Children With ADHD Collaborative. Through the Extranet, teams were able to:

- Find out about conference calls
- Enter monthly data for their improvement project and generate reports
- View and download documents being shared within the Collaborative
- Access the list-serve archive

The graphs below represent the four process and two outcome measures reported by the North Carolina teams during the collaborative to improve care for children with ADHD. The data are aggregated across the eleven final participating North Carolina sites. Although a total of eleven sites submitted data on the measures during the course of the project, the submission of data was not consistent across all teams during each of the eleven months of the collection of data. Four teams submitted data during November 2001, the first month of the collaborative. The high point for data submission was reached in June 2002 when 9 teams submitted data. The last month of the collaborative, September 2002, only four sites submitted data. The above graphs are annotated with the number of sites reporting each month.

Process Measures

Graphs number 1-4 are run charts (see pps.12 and 13) and report the aggregated performance of the participating teams on the four process measures during each month of this collaborative. Table 1 identifies the process measures and findings based on the trends reported in the run charts.

Table 1: Monthly Process Measures

Process Measures	Findings
Graph 1 Percent of patients with the benefits and risks of treatment options explained	The trend increases from 45% in November to 70% in March, and then drops to 58% in May. In June the trend increases again reaching the highest point in September 84%.
Graph 2 Percent of patients with a structured diagnostic assessment in chart	41% of patients have a structured diagnostic assessment in their chart during the first month of the collaborative. The percent steadily increases and reaches 60% in March. After a decline to 50% in April, the trend increases slightly for 2 months, loses a few points in July and August, and reaches the high point of 75% at the end of the collaborative.
Graph 3 Percent of patients with a written care plan in chart	The trend line for this measure increases during the collaborative, starting at 53% in November and drops slightly in February to 45%. The trend gradually increases until June, reaching 78% and drops again in July and August, down to 65%. In September, however, 91% of patients are reported to have a written care plan in their charts.
Graph 4 Percent of patients with identified goals documented on their care plan	In November 38% of patients have identified goals documented in their care plan. By February 55% of patients have this information documented. The percent drops in April but climbs to 68% in July and August, the high points for the project. In September the trend decreases slightly to 60%.

Outcome Measures

Graphs 5 and 6 are run charts (see page 13) or linear trends of the outcome measures for the collaborative. The two outcome measures are:

1. The percent of patients who maintain an acceptable level or improve functioning by 25%; and
2. The percent of patients who maintain an acceptable symptoms score (≤ 18) or improve their symptoms score by 25%.

Table 2 lists the outcome measures and the findings based on a review of the run charts. Outcome measures were calculated from January through September 2002.

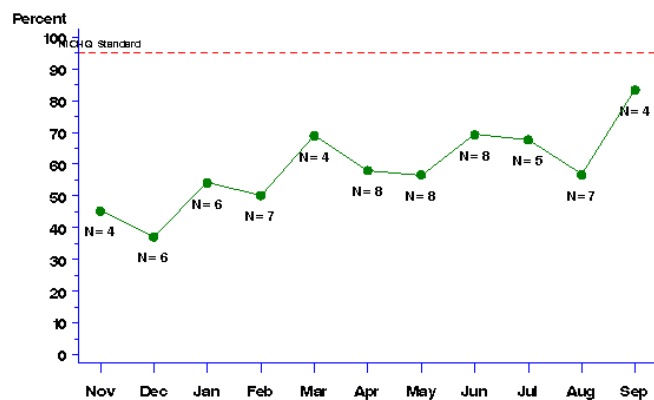
Table 2: Monthly Outcome Measures

Outcome Measure	Findings
Graph 5 Percent of patients who maintain an acceptable level or improve functioning by 25% or more	In January 15% of patients maintained an acceptable level or improved functioning by 25% or more. The percent increases to 37% in March. The trend steadily increases through the month of July, reaching 40%. Following a slight drop in August, the high point is reached in September 51%.
Graph 6 Percent of patients who maintain an acceptable symptoms score or improve symptoms score by 25% or more	25% of patients maintain an acceptable symptoms score or improve symptoms score by 25% during the month of January. In March this measure reaches 41% and drops 10 percentage points by April. The next 4 months have slight increases and decreases, maintaining a relatively flat trend. The high point is reached in September when 56% of patients are reported to have maintained an acceptable symptoms score or have improved their symptoms score by 25% or more.

Summary of Results – North Carolina Teams (see Tables 1 and 2, pps. 13 and 14)

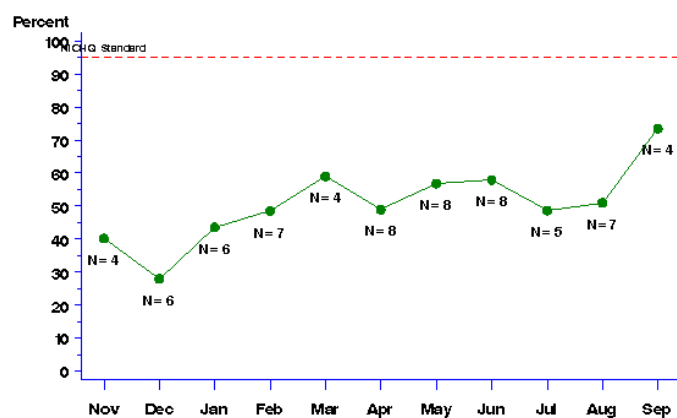
1

Percent of Patients with Benefits/Risks of Treatment Options Explained
NC Aggregate



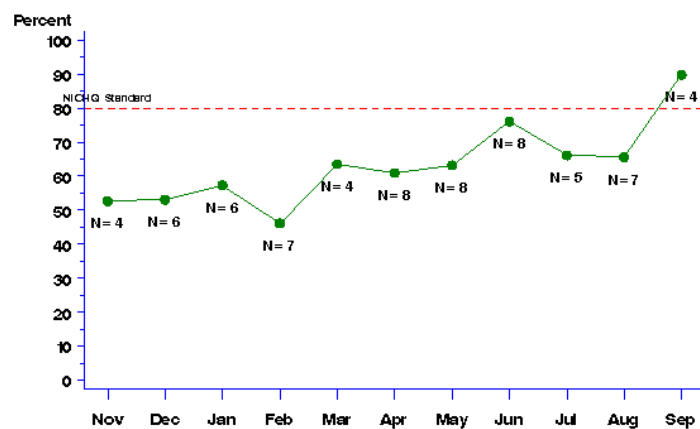
2

Percent of Patients with Structured Diagnostic Assessment in Chart
NC Aggregate



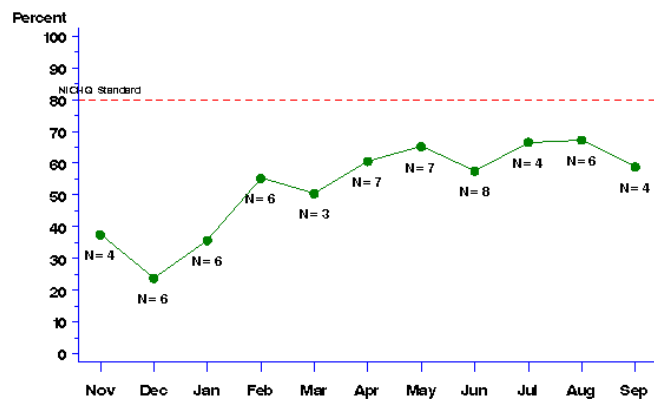
3

Percent of Patients with Written Care Plan in Chart
NC Aggregate



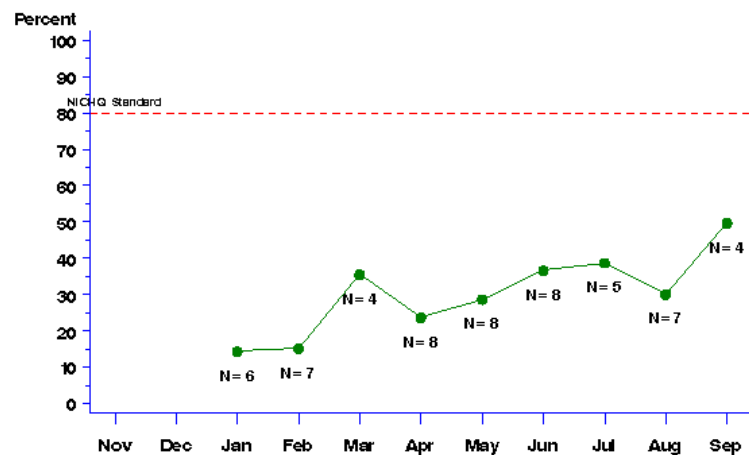
4

Percent of Patients with Identified Goals Documented on Care Plan
NC Aggregate



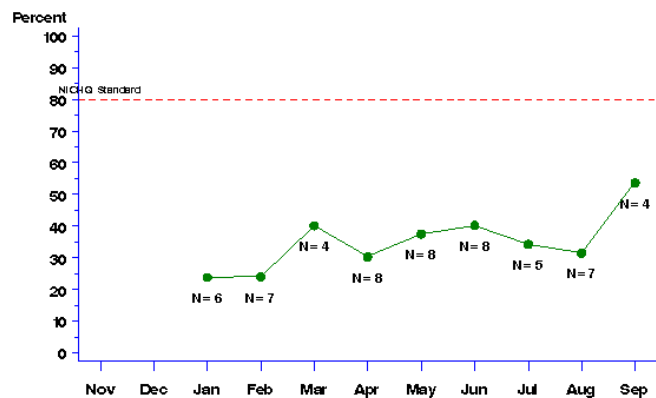
5

Percent of Patients Who Maintain an Acceptable Level or Improve Functioning by 25%
NC Aggregate



6

Percent of Patients Who Maintain an Acceptable Symptom Score or Improve Symptom Score by 25%
NC Aggregate



Summary

Results

All four of the processes measures improved by 30% or more during the nine months of the collaborative. The process measures that showed the most improvement when analyzing aggregated measures on the run charts are:

1. Percent of patients with the benefits and risks of treatment options explained, and
2. Percent of patients with a written care plan in chart.

Both outcome measures improved during the collaborative. The percent of patients who maintained acceptable symptoms score or improved that score by 25% or more increased by 31 percentage points from January (n=6 sites) to September (n=4 sites). A greater percentage of patients improved their functioning or maintained acceptable functioning, increasing from 15% of patients from 6 sites in January to 56% of patients from 4 sites in September. Although these results are limited by the variability in sites submitting data each month during this project, overall there is a positive trend in improving processes and outcomes.

The dramatic success of the teams in improving care for children with ADHD demonstrated that pediatric providers could improve systems of care and the outcomes that children with this condition experience. By implementing the AAP Guidelines using the Care Model for Child Health framework the symptoms and function of participating children improved. Primary care clinicians, their office teams and their community school and mental health providers were able to work together as partners with children and families. Family satisfaction and provider satisfaction improved as a result of a more comprehensive and organized approach to the care of these children.

The collaborative served to test and refine practical measures of processes and outcomes that practices and systems could use to track improvement, and develop exemplar models of care that could facilitate dissemination by demonstrating the feasibility of improvement.

A National Summit was conducted by NICHQ in November 2002. Sandhills Pediatrics and East Carolina University Pediatrics presented their findings in Orlando Florida at that conference. Representatives from the NC Department of Public Instruction also attended the Summit to learn about the collaborative methodology as well as the ADHD content. As a result, plans are underway for collaboration between DMA and DPI to disseminate information from this project to strengthen linkages between practices, schools and families to improve care for children with ADHD.

Bibliography

1. American Academy of Pediatrics. Clinical practice guideline: diagnosis and evaluation of the child with attention-deficit/hyperactivity disorder. Pediatrics 2000; 105:1158-70
2. Homer, C, Goldmann D, Kleinman L. Improving the Quality of Health Care for Children in Health Care Systems. Health Services Research. 1998; 33(4, part 2): 1091-109.
3. Langley, G., Nolan, K., Nolan, T., Norman, C., Provost, L. (1996) The Improvement Guide. San Francisco, CA: Josey Bass.
4. Pelham, W. (1999) The NIMH multimodal treatment study for attention-deficit hyperactivity disorder: just say yes to drugs alone? Canadian Journal Psychiatry, Vol. 44, 981-989

5. Rogers, Everett M. (1995) Diffusion of Innovation, 4th Ed. New York, NY, Free Press, c1995.
6. *Treatment of Attention-Deficit/Hyperactivity Disorder*. Summary, Evidence Report/Technology Assessment: Number 11. AHCPR Publication No. 99-E017, December 1999. Agency for Health Care Policy and Research, Rockville, MD. <http://www.ahcpr.gov/clinic/adhdsum.htm>
7. Wagner, E, Austin, B & Von Korff, M (1996) Organizing Care for Patients with Chronic Illness

Appendix A

EXPERTS CONVENED SEPTEMBER 13, 2000

<i>Collaborative Chair and Co-Chair</i>	
Mark Wolraich, MD	Professor, Chair Vanderbilt University
Peter Jensen, MD	Asst Professor, Faculty Columbia U School of Med
<i>Experts</i>	
Jonathan Brush, PhD	Harvard Vanguard Medical Associates Boston, MA 02116
Eugenia Chan, MD	Health Svcs Research Fellow, Faculty Boston, MA 02115
John Dempsey	Assistant Principal Edward Devotion School Brookline, MA
Harwood Egan, MD	Physician MGH-Revere Health Associates
Jeff Epstein, PhD	Asst Professor, Faculty Duke University Medical Center ADHD Program
Harlan Gephart, MD	Pediatrician, Clinical Professor General Pediatrics - Group Health Medical Director Center for Attention Deficit Disorders Seattle, WA
Maureen Gill, MSW	CHADD Representative, Faculty Chantilly, VA 20151
Charles Homer, MD, MPH	Executive Director NICHQ, Co-Chair 135 Francis Street Boston, MA 02215
Daniel Hyman, MD	General Pediatrician/Erdenheim Pediatrics Med Dir/Children's Health Net Children's Hospital of Philadelphia Philadelphia, PA
Carole Lannon, MD, MPH	NICHQ AAP Liaison, Faculty UNC – Chapel Hill, NC

**William Pelham, Jr.,
PhD**

Professor, Faculty

SUNY Buffalo

James Perrin, MD

Assoc Professor, Faculty

Mass General Hospital, Div of Pediatrics

Lloyd Provost

Consultant, Faculty Associates in Process Improvement

Austin, TX 78731-6053

APPENDIX B

CONDITION SPECIFIC CARE MODEL FOR CHILD HEALTH: Improving Care for Children with ADHD

Community Resources and Policies

- Form partnerships with schools, mental health providers, pharmacies to implement ADHD guidelines and policies that support chronic care
- Identify key contact at school for each child with ADHD
- Seek input from school teachers/counselors for assessment, diagnosis, monitoring and treatment plans
- Educate parents about their rights and requirements for obtaining appropriate educational services through 504 and IDEA

Health Care Organization

- Encourage coordination among state and local health plans of chronic illness guidelines, measures and care resources
- Use an effective improvement strategy that results in comprehensive system change in the areas described above
- Include measurable goals for improving health care for children with ADHD as part of the organization's annual business plan
- Allocate leadership and resources (staffing and financial) to pilot team for entire 12 months of ADHD Collaborative and for the spread of improvements after the initial pilot team demonstrates success
- Health plans cover benefits to promote good ADHD care, including assessment, monitoring, medications and behavioral therapy, and visit and non-visit follow up, and access to appropriate specialty services (visit and non-visit consultation)
- Create incentives for providers to improve ADHD care and implement Care Model for Child Health

Family and Self-Management Support

- Emphasize the patient's and parent's active and central role in managing their (child's) illness
- Enable children and parents to begin an educational process about ADHD and its management, community resources and self help materials at the time of diagnosis and periodically thereafter, according to family needs and changing information
- Enable parents to establish connections to social support at the time of diagnosis and periodically thereafter including through links with parent and child support groups such as CHADD
- Perform standardized assessments of self-management knowledge, skills, confidence, supports and barriers
- Develop a written ADHD Management Plan for every child with ADHD and practice shared goal setting with child (age approp) and family
- Assure regular collaborative care planning and assistance with personalized problem-solving

Delivery System Design

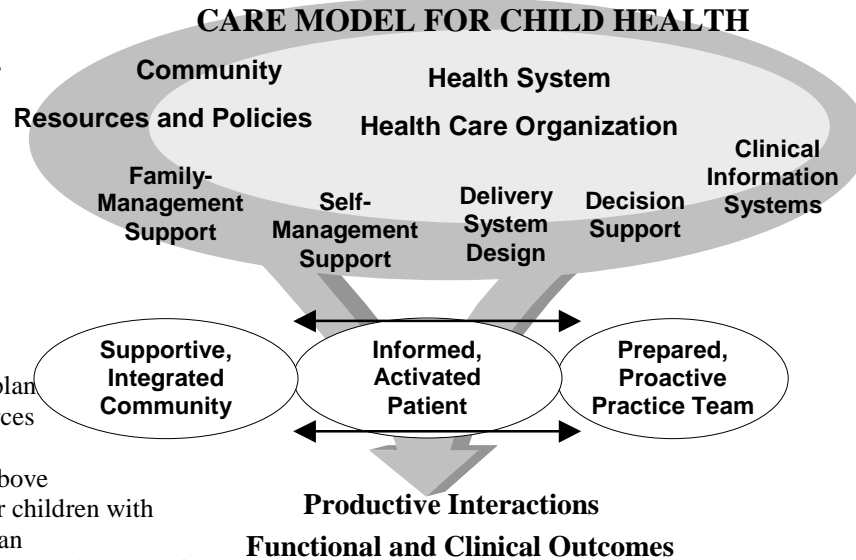
- Define roles and delegate tasks, including "home" team (practice team, school, parents and MHPs)
- Provide care in planned visits based on AAP Guideline recommendations
- Assure continuity with primary care team
- Ensure regular follow-up using visit and non-visit care according to AAP Guideline recommendations

Decision Support

- Establish links with specialists including educational, behavioral and mental health specialists
- Embed evidence-based AAP Guidelines for the Assessment, Diagnosis and Treatment of ADHD into daily clinical practice
- Partner with mental health provider (MHP) to identify opportunities for improvement in primary care of children with ADHD and appropriate criteria for referral to MHP
- Utilize provider education modalities proven to change practice behavior
- Provide effective behavior management strategies to parents and teachers to target specific behaviors at home or school
- Provide referral to behavior therapy programs if additional behavioral therapy is warranted
- Inform patients of guidelines pertinent to their care

Clinical Information Systems

- Identify patients with ADHD and use ADHD registry to track clinically useful and timely information
- Use registry reports, and data for feedback for providers and patients
- Use form letters, mailing labels, or electronic communication etc. to facilitate communication with patients to assure timely planned follow-up
- Enable the identification and proactive care of relevant patient subgroups within the registry
- Facilitate individual patient care planning
- Consider using web-based data collection systems to facilitate collection of relevant data from family and school and scoring of ADHD scales for assessment, diagnosis and monitoring



APPENDIX C

PAPER REGISTRY

By the 7th of each month for data collected the month prior, please fax or e-mail the following report to Sarah Furber at (919) 843-7351, e-mail woodbury@unc.edu. Please call Sarah with any questions at (919) 966-9397. Thank you.

Measure	How to calculate the Numerator	How to calculate the Denominator	Numerator/ Denominator	Percent
Percent of patients with structured diagnostic assessment	Total patients with the Initial Parent Evaluation and the Initial Teacher Evaluation filled out as noted on the Patient Visit Flowsheet, or another diagnostic assessment rating scale noted on the ADHD Primary Care Initial Evaluation Form	Total number of ADHD patients in your practice	____/____	%
Percent of patients with care plan documented in their medical record	Total patients with care plan noted on the Patient Visit Flowsheet	Total number of ADHD patients in your practice	____/____	%
Percent of patients with individual goals listed on care plan	Total patients with individual goals documented on their care plan noted on the Patient Visit Flowsheet	Total number of ADHD patients with a documented care plan	____/____	%
Percent of patients with risks/benefits of treatment options explained	Total patients with risks/benefits of treatment options explained noted on the Patient Visit Flowsheet	Total number of ADHD patients in your practice	____/____	%
Percent of patients who maintain an acceptable level or improve functioning	-Number of patients who function without impairment (Acceptable level of functioning="Yes" on the Patient Visit Flowsheet), Plus -Patients at an <i>unacceptable</i> level of functioning that have a 25% lower score on the most recent Teacher or Parent NICHQ Vanderbilt Assessment <i>Follow-Up</i> Scale (average items 19-26) compared to the baseline score on the Teacher or Parent NICHQ Vanderbilt Assessment Scale (average items 48-55). If a child shows a 25% improvement on either the parent or teacher scales count him in the numerator.	Total number of ADHD patients in your practice	____/____	%
Percent of patients who have an acceptable symptom score or lower their symptom score	-Number of patients who maintain an acceptable symptom score (total score <= 18 on the Teacher or Parent NICHQ Vanderbilt <i>Follow-Up</i> Scale), Plus -Patients <i>without</i> an acceptable symptom score that have a 25% lower score on the most recent Teacher or Parent NICHQ Vanderbilt Assessment <i>Follow-Up</i> Scale (total items 1-18) compared to the baseline score on the Teacher or Parent NICHQ Vanderbilt Assessment Scale (total items 1-18). If a child shows a 25% improvement on either the parent or teacher scales count him in the numerator.	Total number of ADHD patients in your practice	____/____	%

APPENDIX D

Assessment Scale:

1. **Forming Team:** An appropriate team has been formed and a pilot population identified. An aim focused on the ADHD population has been developed and work on baseline measures has begun.
2. **Activity But No Changes:** The team is actively engaged in the project (research, measurement, interviews, database development, etc.). The team aim and pilot population are consistent with the charter for the collaborative. Measures related to the aim have been defined. The team understands the Care Model for Child Health. PDSA cycles to test changes in office practices have been planned.
3. **Modest Improvement:** Implementation of the Care Model for Child Health has begun for the pilot population. Initial cycles to test changes have been completed and implementation activities begun for some components of the model. There is some evidence of improvement in process measures related to the team's aim. For example, the percent of children being treated for ADHD with a completed structured diagnostic assessment has increased by 20%.
4. **Significant Progress:** The Care Model for Child Health has been implemented for the pilot population. There is evidence of improvement in outcome measures related to the team's aim. For example, 50% of children being treated for ADHD either function without impairment or have experienced an improvement of 25% or more in function. The team is at least halfway toward accomplishing all the goals stated in their aim. Plans for spread of Care Model for Child Health as outlined in the team's aim are in place.
5. **Outstanding Sustainable Results:** The team has successfully implemented all components of the Care Model for Child Health in the pilot population. All goals in the team's aim have been accomplished. Outcome measures appropriate to the chronic population indicate breakthrough improvement and are at national benchmark levels. 90% of children being treated for ADHD either function without impairment or have experienced an improvement of 25% or more in function during the collaborative. 80% of patients being treated for ADHD have experienced an improvement of 25% mean score in symptoms. Work to spread the care model to other patient populations, other providers, or other sites is well underway.